A PROGRESSIVE LOOK AT INCREASING FOLLOW-UP AFTER UNIVERSAL NEWBORN HEARING SCREENING REFERRALS

Capstone Project

Presented in Partial Fulfillment of the Requirements for

the Doctor of Audiology

in the Graduate School of The Ohio State University

By

HEATHER L. VAUGHT, B.A.

◊◊◊◊◊

The Ohio State University
2012

Capstone Committee:

Christina M. Roup, Ph.D., Advisor

Gail M. Whitelaw, Ph.D.

Christine M. Goodman, Au.D.

Approved by:

_____

Advisor

ABSTRACT

Universal Newborn Hearing Screening (UNHS) has continued to grow in the United States to be a very successful program when it comes to identifying children who may have hearing loss. However, this program currently lacks an appropriate national data management system for tracking the progress of patients throughout diagnostic evaluations and follow-up. A staggering number of children who do not pass their initial UNHS are subsequently lost to follow-up and presumably never receive diagnostic evaluations or early intervention. Several programs exist elsewhere in healthcare that provide incentives to parents or participants to follow-up and to maintain a line of contact with a medical home. Adding a national database that providers can access to check on patient progress and providing the patients with incentives to follow-up may help to continue the increasing number of children and their families who benefit from early identification of hearing loss.

DEDICATION

The number of people who have been encouraging during this process is incredible. My parents and my husband have been so supportive (both financially and emotionally) and I am proud to present to them the result of eight years of blood, sweat, earwax, and tears.

Dr. Gail Whitelaw has acted as an incredible advisor and mentor with the patience of a saint. Thank you for believing in me even when I had little faith in myself.

Dr. Christy Goodman, you can finally take your boots off. Thank you.

VITA

October 29, 1985 ..... Born – Troy, OH

2006 ..... B.A., Speech and Hearing Science
The Ohio State University

FIELDS OF STUDY

Major Field: Audiology

According to the Central Intelligence Agency, the world is quickly approaching a population of 7 billion. The current estimate as of July 2011 was 6,928,198,253. Breaking down the worldwide birthrate looks something like this: 131.4 million births per year; 360,000 births each day; 15,000 births per hour; 250 births per minute; or four births each second of every day (CIA.gov, December 2011). Looking at the vast number of newborns that our world has on a daily basis begs the questions from a healthcare perspective, or more accurately in this case an audiologic perspective, how many of these babies are screened for hearing loss at birth? With hearing loss occurring in roughly 5,000 births per year in the United State alone, the number of hard of hearing infants worldwide is staggering (Thompson et. al. 2001).

Snyderman and Williams (2003) point out that today's healthcare system is largely reactive rather than proactive, with sporadic interventions from physicians; in this system of infrequent care, the care received is not only more expensive but also inefficiently deployed. Using cutting edge technology to prevent disease and illness from spreading, or to effectively treat a current ailment may not be rewarded, and many physicians are being held in the pattern of reactive care due to insurance and reimbursement policies. This prevents innovators in the medical field from lowering the cost of care by improving upon current treatment methods. Planning for health promotion or disease prevention is often not included in current insurance plans, nor are

many politicians advocating for it. Providing maximum benefit for the patient requires prevention or early detection and intervention. Planned care visits with routine screening and testing is an important feature to redesigning the current health care system (Bodenheimer, Wagner, & Grumbach, 2002). With no fewer than 125 million Americans having at least one chronic condition, this system is bound to fail (Snyderman & Williams, 2003). Chronic conditions also account for more than $1 trillion in health care expenditures annually (Snyderman & Williams, 2003). This number will not decrease with the rising population of the United States unless the system changes. Access on a continuous basis is needed for the most beneficial care, regardless of age; prospective care is the nation's answer to the financial management of health issues. Providing patient resources by means of education or linking provider care strategies with community programs is one way to address preventative care (Bodenheimer, Wagner, & Grumbach, 2002). The Bodenheimer et. al. study also layed out this data on managed care: 9.6 million patients receive care on at more than 700 community health centers; these centers are funded by the Federal Bureau of Primary Health Care, Medicare, Medicaid, and state health departments; more than 64% of those receiving care are ethnic minorities, and patients who live below 200% of the poverty line. With statistics suggesting that many already struggle financially, it's a wonder that our current health care system has survived as long as it has. Bodenheimer et. al. (2002), referred to a change in the health care climate in the mid- to late- 1990s. This change was from the "old" ways of reactive care to a more management-based model often used for chronic illness.

With the information provided by the Bodenheimer and Snyderman studies about the current ineffective state of healthcare in the United States, a look at the newborn hearing screening programs may suggest that they are relatively successful. Evaluating the percentage of newborns screened and the amount of early intervention that has been provided to families with newborns with hearing loss provide a positive outlook. Yoshinago-Itano (2001; 2003) has published extensive research suggesting the positive impact of early detection on intervention services and outcomes for the children to whom these services are provided. However, upon closer examination, the need for improvements becomes more evident. This is especially true when appraising follow-up rates for newborns that fail their initial hearing screening at birth (Bolat et. al., 2009; Gaffney et. al. 2010; Hyde, 2005; Kezirian et. al., 2001; Korres et. al., 2008; Korver, 2010; Krishnan, 2009; Kumar & Mohapatra, 2011; Morton 2006; Roeve et. al., 2004; Uus, 2006; Shylman et. al., 2010, Spivak et. al. 2009).

The movement of screening hearing for newborns has spread worldwide (Yoshinaga-Itano, 2003). Not only do developed countries have programs in place, developing nations such as India, Nigeria, Bulgaria, and Turkey are also implementing this measure (Kumar & Mohapatra, 2011; Olusanya et. al., 2005; Rouev et. al., 2004; Bolat et. al., 2009). India has recognized the need for screening newborns as urgent (Kumar & Mohapatra, 2011) and their research has stated that the late identification of hearing loss in children is a "significant public health concern." Bulgaria's programs appear to be run as cost efficiently as any other screening program in their nation (Rouev et.al., 2004). Yet, these nations are struggling with the same issues as the United States:

following up with newborns that do not pass their hearing screening.

Newborn hearing screening protocols often include Auditory Brainstem Response (ABR) and/or a form of Otoacoustic Emission (OAE) evaluation. Otoacoustic emissions evaluate the health of the cochlear hair cells as the sensory component and the auditory brainstem response evaluates the neural transmission of the signal from a healthy cochlear to the auditory cortex (Kirkim et.al., 2008). Programs that include both of these tests usually utilize OAEs at the first screening; an ABR is secondary only if the infant does not pass the OAEs. In order to understand the reasoning behind this, sensitivity and specificity of the tests needs to be understood. Sensitivity is a term used to describe the number of test subjects who are correctly identified as having the disorder (in this case, hearing loss). Specificity looks at correct identification of those who do not have the disorder. Sensitivity and specificity are often trade-offs, however the ideal screening protocol has both high sensitivity and high specificity. In the case of two-step newborn hearing screening programs, sensitivity has a rate of 90.3% and specificity has a rate of 98.5% (Keren et. al., 2002), giving a high confidence in the results and findings of these programs. Model programs in the United States include those in Texas and Colorado. These programs were early adopters of newborn hearing screening programs and have had continued success with meeting Joint Commission on Infant Hearing (JCIH) benchmarks such as the percentage of infants screened before leaving the hospital and also in identifying the need for diagnostic evaluations at a close rate to the JCIH data (Morton & Nance, 2006). Colorado has done well with tracking the development of newborns that were screened prior to three months of age (Yoshinago-Itano, 2003).

Texas programs use a two-step screening method that includes both the use of OAEs and ABR. The two-step program is thought to reduce the number of false-positives that can occur when using a single-step testing battery, as well as lowering the overall referral rate for newborns; both of which are critical in developing a reliable screening program (Iwasaki et.al., 2003). By using this method, the entire auditory pathway as is evaluated and then is broken down in to both sensory and neural components and helps to reduce the chance that children born with auditory neuropathy are missed in the screening process. With a goal of early identification for all hearing impaired children, it is important not to overlook this group no matter how fractional their numbers may be. Current estimates regarding the prevalence of auditory neuropathy range from 0.044% up to 0.23% of newborns (Kirkim et. al., 2008). Colorado has tracked data from their programs that suggest babies who were born in hospitals that have hearing screening programs are more likely to be early identified, 84% of those with hearing loss, as compared to babies who were born in hospitals with no hearing screening program, a mere 8% of those with hearing loss (Yohinaga-Itano, Coulter, & Thomson, 2001). Early identification at an age of less than six months is one of the benchmarks for the JCIH; late identification by their standards is any congenital hearing loss after the age of six months (JCIH 2007).

A hearing loss that is detected at birth may also have other medical implications. Often parents are encouraged to pursue genetic counseling if the etiology of the hearing loss is unknown. Hearing loss may also be the first detectable symptom of a larger medical issue, such as a syndrome, that will require multiple visits to physicians and

specialists –again burdening the parents, and in turn the community, with additional costs. Such conditions include Usher's syndrome, Nance deafness, and Pendred's syndrome, all of which have pediatric onset of hearing loss (Morton & Nance, 2006).

Yoshinaga-Itano (2001) quotes the price range of hearing screenings for newborns to be anywhere from $25.00 to $35.00. Calculating for inflation, this estimate for 2012 would be between $32.00 and $45.00 which is still a reasonable price considering the cost of educating a child with hearing loss, particularly with later identification.

Implications of late identification, late hearing aid fitting, and loss to follow-up are not only detrimental to the infant's future communicative abilities, but they also carry a heavy price tag for the community. The cost of educating a child for one year in an elementary or secondary public school is estimated between $10,000 and $11,000 (National Center for Education Statistics, 2012). Once a child is held back in school or has failed their grade level for the year, this number increases for the next school year based on inflation, additional staff to accommodate the child's needs, and additional intervention services needed (Seligmann, 2001). While some additional funding can be allocated to a child with special needs through government funding and the Individuals with Disabilities Education Act (IDEA), this is often not enough to provide for the rehabilitation of the child as well as the continued learning goals of that year. The federal government will ideally pay up to 40% of the excess cost to educate children who are disabled (Apling, 2004), although it has never met this goal (Seligmann, 2001). The other 60%, in turn, is picked up by the community through increased taxes, school levies, or extra fees. A 2004 current trending report on the status of IDEA showed a significant

increase in the funding from state grants but far less of an increase in the funds allocated for pre-school programs and programs that serve infants and toddlers with disabilities (Apling, 2004). Requests for the 2005 budget showed a marginal increase of five percent to infant and toddler programs, however, funding for national programs and activities would decrease by 25%. Rather than supplying the full 40% that the government set as the funding goal, the actual percentage funded for the 2005 budget was less than 20% (Apling, 2004). The reality of the number of children who do not do well in school was addressed in the "No Child Left Behind" (NCLB) policy implemented by President George W. Bush (No Child Left Behind Act of 2001). Darling-Hammond (2007) suggested that the policy misidentified the existing problem by focusing on test results rather than focusing on the quality of education that was provided. This policy did little to improve government funding for students who need the extra help, but rather put that financial burden back on the communities while grading the communities based on every child's successful completion of grade levels or graduating from high school. Less than ten percent of a school's budget was supplemented by NCLB (Darling-Hammond, 2007). Special-needs students are in a subgroup so as to not affect the general education population test scores in a school until they "catch up" by the school's standards, but by doing so their subgroup will never reach the 100% passing goal set by NCLB (Darling-Hammond, 2007).

Indicators for newborn hearing screening programs are important to look at as well. According to the JCIH, quality indicators for a screening program include having more than 95% of all infants screened by one month of age. Less than 4% of newborns

screened should fail the initial screening and subsequent re-screening. (JCIH, 2007). This was determined by the prevalence of hearing loss in the general population.

The JCIH committee outlined a goal that is summarized by "1-3-6." All infants should have their hearing screened by one month of age. Those who fail the screening should have a follow-up re-screening and subsequent diagnostic evaluation to definitively confirm hearing loss by the age of three months. All infants with a confirmed hearing loss should be receiving intervention services by the age of six months.

JCIH (2007) also described some of the current challenges in meeting these benchmarks. High on that list is the fact that we are currently losing too many infants between screening and re-screening as well as between re-screening and diagnostic evaluation. More steps in a screening program, especially those after an infant has been discharged from the hospital, is one factor that is connected to a high loss-to-follow-up rate (Korres et. al., 2008). Consistent and stable funding at both the state and federal level are also barriers. Reimbursement and inter/intra-state data management systems need extra attention. For example, in the state of Ohio currently there is no universally accessible database to track the progress of a newborn that did not pass their hearing screening. One must contact the Ohio Department of Health to follow-up on a newborn, and even then current HIPAA laws make it difficult to obtain that information, specifically if one is not actively involved in the child's current care or if one was previously involved but the parents have not signed a release of information. In an attempt to secure health information from wrongful use, the law has made it more difficult to gain information regarding to continuity of care for a patient without express

written consent. Hospitals may see an infant at birth to screen but may never see that child again due to location, travel distance, or family situations not conducive to pursing further diagnosis or potential treatment. Some hospitals still use only a paper tracking system which does not interact with the electronic health record (Jha et. al., 2009). Additionally, with more children being identified earlier there is a growing need for professionals who provide early intervention services.

A study by Gaffney, Green, and Gaffney (2010) looked at information regarding universal newborn hearing screening and the results (pass or refer). They also looked at how many cases were lost to follow up. In 2005 the "lost to follow-up group" was more than half of the population who did not pass their screening at birth: 59.9% (Gaffney, Green, & Gaffney, 2010). Results improved for 2006 to 46.3% lost to follow-up, but this is simply not enough. The main reason cited in the research for losing these infants was "unable to contact/unresponsive/unknown" (Gaffney, Green, & Gaffney, 2010). Nations that are still developing programs are also losing infants to follow up. However, some have found that adequate relay of information to the parents plays a role in this. In Turkey, delivery personnel who were in close contact with the parents during the birth of their child emphasize the importance of hearing screenings and managed care. This system saw a rise in the number of infants screened between 2004 and 2008 (Bolat et. al., 2009). This rise came from more than the increased number of screening programs. The hospital personnel who were present in the delivery room and in obstetrics services maintained contact with the parents of a newborn to reinforce the importance of hearing screenings and their results. The number of children lost during this process continues to

be large, even after diagnosis. The next step was to determine a treatment plan for the child. Spivak et. al. (2009) looked at what factors lead to losing infants who have a confirmed hearing loss but have not yet been fit with hearing aids. They found that more infants were lost to follow up (44%) than were fit before six months of age (39%). The highest predictors for losing a child to follow-up were diagnosis after three months of age and unilateral hearing loss; these predictors were followed closely by being enrolled in the Medicaid program and having a conductive hearing loss (Spivak et.al., 2009). Emphasizing the consequences of an undiagnosed or untreated hearing loss rather than minimizing the possible outcomes increases parental compliance; early initiation of follow-up also increases compliance (Spivak et. al., 2009).

Since the year 2000, there has been a significant increase in infants screened. As a country, the United States has seen the number rise from a mere 38% of infants being screened to 95% (JCIH, 2007). An increase in hospitals utilizing UNHS and an increase in states mandating the screenings are likely causes for the rising trend. There is a general need for recent information regarding the current standing of JCIH's 1-3-6 goal. Most information is three-to-five years old at this point. One theory for this is that once UNHS was in place in all 50 U.S. states and had been proven effective, the need for calculations decreased; perhaps 95% is "good enough." Of the data that exists, the most concerning numbers seem to fall in the category of "lost to follow-up." How can audiologists and other medical professionals, encourage parents to follow-up with a sense of urgency? Are failed hearing screenings alone in this category, or are other failed health screenings experiencing the same loss to follow-up? According to Morton and

Nance (2006), metabolic screening programs for newborns and infants have an extraordinarily high follow-up rate. This may be due to the fact that physicians are the primary professionals to follow-up with regarding these screenings, whereas with hearing screening referrals a physician may need to utilize the skills of an audiologist; this creates another step in the process to diagnosis. Metabolic screenings also test for several life-threatening conditions such as phenylketonuria, galactosemia, and Sickle Cell Disease, to name a few. Parents may be more familiar with the life-threatening nature of these disorders than the quality-of-life impairment a hearing loss can hold for a child and their family, making follow-up more "urgent" in their minds.

When presenting information to a parent, either before or after a newborn hearing screening, research suggests that checking for understanding by asking a few simple questions can greatly impact their awareness of the need for the screening (Baker et. al, 2004). Maternal education level plays an important role in this as well as education of the screening personnel. According to several studies, maternal education level serves as a proxy to determine a family's socioeconomic status and possibly the geographic location of the family (Boyle et. al., 2006; Baker et. al, 2004; Speros, 2005). The socioeconomic status then lends itself to determine if the family is eligible for Medicare or Medicare-like services. Effective information transfer from screening personnel to the parent is impacted by how well the personnel understand the test and all of its potential outcomes. Pender and de Looy (2004) suggested the need to have a reliable tool to assess the clinical skills and attitudes of clinicians over time. Poor understanding on the part of the personnel does not meet the needs of a new parent, especially if personnel are

uncomfortable talking about all possible outcomes of the screening, particularly adverse outcomes. Clinicians who are administering the screening should be able to talk to the parent about potential outcomes of the screening, any risks involved in it, significant implications (medical, social, and financial) of the outcomes of screening, and any follow-up necessary (Baker et. al., 2004). These personnel should be able to answer, or find answers to, parental questions. Competence on a professional level, such as that of the screener, demands more than just a demonstration of isolated skills (Pender & de Looy, 2004). An effective transfer calls for the ability to portray this information in a fashion so that the patient, or parents of the patient in this case, can access and understand the information. The Pender study suggested having clinicians rate their self-evaluated competence on a visual analog scale without numerical value; they found that most clinicians could realistically rate their skills using this technique when accompanied by a rubric outlining competence goals (2004). Kogan et. al. (2009), confirm the need for a "work-based evaluation tool;" the study suggested that self-regulation by clinicians with the most experience in the system is effective. Baker et. al. (2004), advocates that by structuring the presentation of information to parents, those with lower education levels are given a boost in understanding and comprehension by being provided with multiple access points to information (auditory as well as visual) and by having their comprehension of the information provided checked. The Baker study then begged the question of who can provide the information needed to these parents? Audiologists seem like the logical answer to this question, however their time is rarely spent in this setting. Rather, the information is generally provided to the parent by a volunteer, nurse,

pediatrician, or speech-language pathologist. Kumar and Mohapatra (2011) found that regardless of the setting, medical or speech and hearing centers, institutions preferred to have an audiologist on hand to provide parents with verbal and written information regarding the status of their infants hearing screening results –especially when the result is a "refer". This study also suggested that "the concerned professional should be recruited for the purpose" (Kumar &Mohapatra, 2011). No one is more concerned about pediatric hearing loss than an audiologist.

The health literacy of a patient may be another important factor for which to account. Health literacy has been defined by several organizations including the American Medical Association and the Health People 2010 initiative; the most complete definition comes from the World Health Organization: "the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways that promote and maintain good health" (Speros, 2005, p. 635). A person's health literacy level may fall below their general literacy level, a concerning fact when 40-44 million Americans are functionally illiterate and another 50 million have marginal skills in literacy (Speros, 2005). An interactive explanation of health information and assessing a patient's comprehension of information may help to enhance their health literacy as it relates to follow-up for a failed hearing screening. Speros (2005) reported that consequences of increased health literacy include "improved self-reported health status, lower health care costs, increased health knowledge, shorter hospitalizations, and less frequent use of health care services" (p.637). Health knowledge is increased when health system contributors, such as hearing screeners, help patients

promote good health by providing them with access to information and guiding them through an understanding of the information provided. The information provided at a newborn hearing screening could range from how the screening was performed, what the results mean, and how to follow-up, to contacts for early intervention when necessary. Speros (2005) suggested that promotion of health literacy on the part of the screener can be as simple as using "plain" (e.g. non-technical) language, speaking slowly, using visual aids when appropriate, and limiting the amount of information transferred at one time to the patient. Once the parental health-literacy level has been determined, Korres et. al. (2008), suggested that the distribution of educational literature to the parents along with a discussion may vastly reduce the number of referred infants who become lost to follow-up.

A small study by Thompson and Thompson (1991) revealed that when a parent is concerned about their child's hearing, the first professional they turn to is their physician or pediatrician. This study also revealed that physicians were least likely to agree with parental concern while non-physicians, such as audiologists or nurse practitioners, were most likely to agree. A study by Olusanya et. al. (2005), confirmed this idea more than ten years later. This study found that the majority of physicians recommended diagnostic evaluations to detect infant hearing loss after the first year of life and that parental concern, rather than physician concern, was the most common reason for screenings (Olusanya et. al., 2005). Common reasons in both studies that physicians did not immediately take action in regards to concern of a hearing loss included thinking that the child would "grow out" of their current behaviors that parents interpreted as signs of

hearing loss or thinking that the child was not old enough to have a diagnostic evaluation. Perhaps this is due to two factors: informal screenings (such as whispers, finger rubs, and tuning forks) that may continue to take place in a physician's office are often inadequate based on the equipment used and the training of the operator as well as audiologists not having adequate ability to bill for diagnostic testing under Federal guidelines (Thompson & Thompson, 1991). Billing issues for audiologists are being resolved, but informal and inadequate screening methods are still being used. When parental concern is taken into account, the delay of diagnosis for pediatric hearing loss dropped from 10.1 months down to 3.8 months (Thompson & Thompson, 1991). Olusanya et. al. (2005) found that parental concern is still often over looked by nurses or physicians, especially when the concern is voiced by parents who are perceived as poorly educated. In addition to better serving the child's needs, parental concerns can be addressed more quickly when physicians are willing to listen to the parents and make appropriate referrals. With the advent of UNHS, there has been a very measurable effect on early intervention programs. A significant decrease in age of diagnosis was noted for one program in Kansas where age of diagnosis dropped from twelve months to 3.7 months in less than five years following the implementation of a UNHS programs (Halpin et. al., 2010). When children are diagnosed a younger age, there is far less "catch-up" and much more progressive habilitation. The Halpin et. al (2010) study also brought to light the fact that more children with mild or moderate hearing losses are being seen at an earlier age than in the past. UNHS has had a positive impact on children who receive early intervention services at a younger age. Yoshinago-Itano (2003) highlighted that children with hearing

loss who were born in hospitals with UNHS programs are more likely to develop language skills at similar rates to children with normal hearing. Children who are identified as having a hearing loss after the age of six months often struggle to catch-up to their typically developing peers due to the greater than average acquisition of language skills that are needed (Yoshinago-Itano, 2003).

There are a few programs already in existence that offer incentives to the parents to follow-up with a professional. An outstanding program is in existence in Mexico which provides incentives with an emphasis on family health. The program, "PROGRESA", offers a cash incentive to families who obtain preventative care (Gertler & Boyce, 2001). Research has found that this program lowered the overall number of visits with providers and lowered the incidence of severe illness (Gertler & Boyce, 2001). Once a family has met their health goals, cash is transferred to the account of the mother in the family. This strategy is designed to keep the funds in the household and improving the quality of care for children in regards to education and nutrition. There is disagreement as to whether cash transfers are the best option for providing incentives; direct provision of food or services may be the better alternative (Gertler & Boyce, 2001). Other programs that offer health and learning incentives includes those offered by Miami Valley Women's Center (womenscenter.org/classes.html, February 2012): Making Outstanding Mothers and Earn as You Learn. Both of these programs offer "Baby Bucks" for attending classes, keeping doctor's appointments, starting a savings account, or writing reports about suggested parenting material. The "Baby Bucks" are redeemable at their Baby Store for necessities such as diapers and baby food or for luxuries like a

playpen or baby toys. Programs similar to these are one possible solution for providing incentives for parents of children with suspected or confirmed hearing loss to follow-up on screening and evaluation results. A potential model for this would be one of the current marketing strategies used in healthcare. Programs such as IncentiveLogic (IncentiveLogic.com, December 2011) and IncentOne (IncentOne.com, December 2011) have online portals where patients and businesses alike can track their performance and outcomes. Modeling a UNHS follow-up program from this could use the rewards mentioned earlier that could be luxuries for some of the patient's families or necessities for other families. Points earned in the system may be applicable to purchasing diapers and food as well as early intervention sessions or hearing aids if applicable. Enticing the entire financial spectrum of potential patients would be important in order to help maintain a high rate of compliance for such a program.

These incentive programs could also incorporate those patients who are in need of early intervention following the confirmation of a diagnosis of hearing loss. Encouraging a partnership between audiologists and speech-language pathologists remains an important factor in a successful early intervention program since proper language development is significantly correlated to age of identification of hearing loss and age of enrollment into early intervention services (Yohinaga-Itano, 2003). The beginnings of an excellent early intervention program start with early detection of hearing loss, usually through UNHS. The Colorado Home Intervention Program (CHIP) has a structured system in place and would be a model to follow for creating or re-vamping programs elsewhere. The program has evolved, initially beginning at the University level then

moving to the Department of Public Health and finally being housed in the Department of Education. This program utilized trained professionals as providers including: deaf educators, early childhood special educators, bilingual educators, social workers, and psychologists in addition to the speech-language pathologist and audiologist. Through this model, services are not provided directly to the child, rather these professionals help the parents of a diagnosed child make informed choices about the intervention that their child will receive (Yoshinago-Itano, 2003). By utilizing the knowledge of these professionals and their experience in the field, families are provided appropriate information and direct referral services that could yield quicker results (Thompson and Thompson, 1991).

In order to incorporate early intervention services and referrals to an incentive based program, the family would be awarded points or vouchers for following through with a scheduled appointment. An example of this would be that the audiologist recommends a speech-language evaluation; the child is seen by the speech-language pathologist who would notify the audiologist of a complete evaluation. Then, through the online portal the family would be awarded the points or voucher. Points may also be given to the family for routine attendance to speech-language therapy sessions. All of this could be tracked in on electronic health record that all providers to the child have access too. Reports and progress notes could then be referenced and shared by the intervention team.

Electronic health records (EHR) are used in between 5% and 59% of hospitals in the United States (Jha et. al., 2009). The wide variation is due to what facilities classify

as “health records;” some parts of patient care may be recorded electronically but not all information may be stored this way. The Jha et. al., (2009) study found that only 17% of physicians used electronic health records despite a large consensus on the potential benefit of such a system. Many of the facilities not using HER cited the financial burden of transferring analog records in to digital records, however the facilities that had implemented EHRs found that physician resistance was the biggest burden, not cost (Jha et. al., 2009). Hospitals and private institutions that are major teaching facilities, located in urban areas, and have dedicated coronary care units were the most likely to have already adopted EHRs (Jha et. al., 2009). Such facilities would be an excellent starting point for a follow-up incentive program also. By showing younger generations of caregivers and physicians the benefit of such systems early on, the systems may be more likely to survive, benefit more families, and spread to other facilities.

The National Center for Hearing Assessment and Management has a system that is based solely around Newborn Hearing Screenings and the follow-up care or intervention that is needed. The system is called HiTrack (hitrack.org, March 2012). It is currently used as a state-wide tracking system in seven of the United States, however it may also be purchased as an annual license for individual hospitals. The price of the software program varies based on the estimated number of babies born at a facility during the license period. HiTrack allows data from screening equipment to be transferred into templates that allow the clinician to track and follow progress of an infant and send information to participating caregivers. Multiple users may access the system and reports can be generated automatically based on the stored screening information, which saves

time and money for the facility. The HiTrack program would be an ideal way to monitor the follow-up care of a newborn that did not pass their initial hearing screening. Using this program on a national level would allow for clinicians to track a child even if they move out of state. Such a system could also send out form letters to parents reminding them of upcoming appointments for the follow-up or EDHI process (Korres et. al., 2008). Allowing the parents access to view the record online and providing links to recommended sources may also improve a parent's health-literacy, as noted previously in this document. Benigeri and Pluye (2003) reported that only one in five links that patients find in their own researching initiatives leads to a relevant website. That study also suggests that improved patient health-literacy can lead to increased patient compliance and a better provider-patient relationship (Benigeri & Pluye, 2003). Virtual support groups can also be formed among the parents. Hear My Dreams (hearmydreams.com, April 2012) is one website where parents can go for appropriate information, although meetings are limited to central Massachusetts. Alexander Graham Bell Association for the Deaf and Hard of Hearing (agbell.org, April 2012) has a wider range of locations for actual meetings, but again has copious amounts of useful and productive information for parents.

Funding may be the major downfall of an incentive-based follow-up program. Ways to help fund the program may be obtained through grants from child- or family-based charities. Since some programs are overseen by the Department of Education, and given all of the current national cuts in educational funding, perhaps programs could shift back in to the Department of Health and receive funding. The Ohio Department of

Education is partnered with a program called KnowledgeWorks (knowledgeworks.org, February 2012) that is advocating a change in high school development and college preparation. KnowledgeWorks is supported by the Bill & Melinda Gates Foundation. While this system does not provide a direct incentive to students to succeed, it assists schools and educational programs in looking at education outside of the current box. By doing so they strive for success in a non-traditional program despite the background or previous experiences of the students they serve. A program such as KnowledgeWorks may be interested in investing in children at an earlier age in order to minimize the learning gap between students with normal hearing's performance and students who were identified with hearing loss (both late and early). When the public is unable to provide these resources on their own and for their own benefit the need for such public-private partnerships arises. The partnerships are then able to provide both the expertise and funding needed (Nishtar, 2004). A global set of norms and principals should then be set to foster such arrangements in order to ensure that the financial backing is not affecting the decisions being made by the professionals for the public. Privatization would involve the transfer of decision-making power to the financial backer in the agreement, whereas a partnership is task-oriented and would be oriented toward providing a sustainable health-based outcome (Nishtar, 2004). Some partnerships such as this already exist. Public advocacy and education has been adopted by the Global Business Coalition on HIV and AIDS (GBC) and the Alliance for Microbicide Development (AMD); Strengthening health services is an interest of the Alliance for Health Policy and Systems Research (AHPSR); and improving access to healthcare products is an initiative the Accelerated

Access Initiative (AAI) and the Global Polio Eradication Initiative (GPEI) (Nishtar, 2004). Partnerships may also interest current hearing aid companies; investing in the identification of their potential future customers would give them a chance to spread their messages and help de-stigmatize hearing loss and hearing aids at an early age. Many corporations are also seeking organizations to aid on their own as they realize a social responsibility. These types of pairings and programs can be profitable for the corporations also, as public interest can produce profitable and sustainable changes in their market (Samii et. al., 2002). Accountability can be maintained through rights and obligations of the financially backing institution that have clearly been spelled out by a regulating committee. A larger community effort to recognize the impact that an un-habilitated hearing loss has on a family and on future community expenses could also change the status of funding such incentive programs.

As a nation, the United States appears to have developed a national Universal Newborn Hearing Screening initiative that compares to programs in other industrialized countries. Programs have rapidly grown from just a few states and hospitals to currently being implemented in all fifty states. National outcomes for the U.S. are now comparable to those reported by the United Kingdom, continental England and other parts of North America (Uus & Bamford, 2006; Morton & Nance, 2006). With this growth comes the need for responsible data management and continued statistical analysis to ensure that programs remain at or above the standards set forth by the JCIH. Current studies demonstrate the need for restructuring follow-up initiatives as rates of follow-up in the U.S. are lower than those of England (Uus & Bamford, 2006; Spivak et. al., 2009;

Gaffney, Green & Gaffney, 2010). Other fields in allied-health have latched on to, and been successful with, an incentive based program. Targets of these programs have been basic healthcare and physicals, as demonstrated by PROGRESA, and preparing a parent for a new baby, as demonstrated by Earn as You Learn programs. Within the scope of hearing screenings, a program should appeal to the entire population of families with children with hearing loss. This means that the incentives should be both those that can meet basic needs for lower income families as well as entice families of a higher socioeconomic status to participate. The idea of helping to provide hearing aids or early intervention is lofty, but not unattainable. Programs within the Department of Health and the Department of Education exist that are already interested in the development of healthy children. These are among the options of potential financial backings for such programs. Without some form of change to the current system children with hearing loss will continue to be "lost" until the school systems catch their poor performance –a far more costly venture than efficient follow-up after newborn hearing screenings.

References

Apling, R. (2004). Individuals with Disabilities Educations Act (IDEA): Current Funding Trends. *CRS Report for Congress* , 1-7.

Baker, H., Uus, K., Bamford, J., & Marteau, T. (2004). Increasing knowledge about a screening test: preliminary evaluation of a structured, chart-based, screener presentation. *Patient Education and Counseling , 52,* 55-59.

Benigeri, M., & Pluye, P. (2003). Shortcomings of health information on the Internet. *Health Promotion International , 18* (4), 381-386.

Bodenheimer, T., Wagner, E., & Grumback, K. (2002). Improving Primary Care for Patients With Chronic Illness. *JAMA , 288* (14), 1775-1779.

Bolat, H., Bebitoglu, F., Ozbas, S., Altunsu, A., & Kose, M. (2009). National Newbon Hearing Screening Program in Turkey: Struggles and implementations betweent 2004 and 2008. *International Journal of Pediatric Otorhinolaryngology , 73,* 1621-1623.

Danhauer, J., Johnson, C., Finnegan, D., Lanb, M., Lopez, I. P., Meuel, C., et al. (2006). A National Survey of Pediatric Otolaryngologists and Early Hearing Detection and Intervention Programs. *J Am Acad Audiology , 17*, 708-721.

Darling-Hammond, L. (2007). Evaluating 'No Child Left Behind'. *The Nation* .

Gaffney, M., Green, D., & Gaffney, C. (2010). Newborn Heairng Screening and Follow-up: Are Children Receiving Recommended Services? *Public Health Reports , 125*, 199-207.

Gertler, P., & Boyce, S. (2001). An Experiment in Incentive-Based Welfare: The Impact of PROGRESA on Health in Mexico.

Halpin, K., Smith, K., Widen, J., & Chertoff, M. (2010). Effects of Universal Newborn Hearing Screening on an Early Intervention Program for Children with Hearing Loss, Birth to 3 Yr of Age. *J Am Acad Audiology , 21* (3), 169-175.

Hayashi, Y., Iwasaki, S., Seki, A., Nagura, M., Hashimoto, Y., Oshima, G., et al. (2003). A model of twho-stage newborn hearing screening with automated auditory braingstem response. *Internation Journal of Pediatric Otorhinolaryngology , 67*, 1099-1104.

Hayes, D. (1999). State Programs for Univerals Newborn Hearing Screening. *Pediatric Clinics of North America , 46* (1).

Hoberg Arehart, K., Yoshinago-Itano, C., Thomson, V., Sbbott Gabbard, S., & Stredler Brown, A. (1998). State of the States: The Status of Universal Newborn Hearing Screening, Assessment, and Intervention Systems in 16 States. *American Journal of Audiology , 7*.

Howse, J., Weiss, M., & Green, N. (2006). Critical Role of the March of Dimes in the Expansion of Newborn Screening. *Mental Retardation and Developmental Disabilities Research Reviews , 12*, 280-287.

Hyde, M. (2005). Newborn Hearing Screening Programs: Overview. *The Journal of Otolaryngology , 34*, s70-s78.

Jha, A., DesRoches, C., Campbell, E., Donelan, K., Rao, S., Ferris, T., et al. (2009). Use of electronic health records in U.S. hospitals. *The New England Journal of Medicine , 360* (16), 1628-1638.

Joint Commission of Infant Hearing. (2007). Executive Summary of Joint Committee of Infant Hearing Year 2007 Position Statement. *Audiology Today Supplement* , 2-28.

Kezirian, E., White, K., Yueh, B., & Sullivan, S. (2001). Cost and cost-effectiveness of universal screening for hearing loss in newborns. *Otolaryngology -Head and Neck Surgery , 124* (4), 359-267.

Kirkim, G., Serbetcioglu, B., Erdag, T. K., & Ceryan, K. (2008). The frequency of auditory neuropathy detected by universal newborn hearing screening program. *Internation Journal of Pediatric Otorhinolaryngology , 72*, 1461-1469.

Kogan, J., Holmboe, E., & Hauer, K. (2009). Tools for Direct Observation and Assessment of Clinical Skills of Medical Trainees: A Systematic Review. *JAMA , 302* (12), 1316-1326.

Korres, S., Nikolopoulos, T., Peraki, E., Tsiakow, M., Karaksitsou, M., Apostolopoulos, N., et al. (2008). Outcomes and Efficacy of Newborn Hearing Screening: Strengths and Weaknesses (Success of Failure?). *The Laryngoscope , 118*, 1253-1256.

Korver, A., Konings, S., Dekker, F., Beers, M., Wever, C., Frijns, J., et al. (2010). Newborn Hearing Screenings vs Later Hearing Screening and Developmental Outcomes in Children with Permanent Childhood Hearing Impairment. *JAMA , 304* (15), 1701-1708.

Krishnan, L. (2009). Universal Newborn Hearing Screening Follow-Up: A University Clinic Perspective. *American Journal of Audiology , 18*, 89-98.

Kumar, S., & Mohapatra, B. (2011). Status of newborn hearing screening program in India. *International journal of Pediatric Otorhinolaryngology , 75*, 20-26.

Moeller, M. P., White, K., & Shisler, L. (2006). Primary Care Physicians' Knowledge, Attitudes, and Practices Related to Newborn Hearing Screening. *Pediatrics , 118* (4), 1357-1370.

Morton, C., & Nance, W. (2006). Newborn hearing screening--a silent revolution. *The New England Journal of Medicine , 354* (20), 2151-2164.

Nishtar, S. (2004). Public-private 'partnerships' in health - a global call to action. *Health Research Policy and Systems , 2* (5).

No Child Left Behind Act of 2001, 20 U.S.C. § 6319 (2001)

Olusanya, B., Eletu, O., Odusote, O., Somefun, A., & Olude, O. (2006). Early detection of infant hearing loss: Current experiences of health professionals in a developing country. *Acta Paediatrica , 95* (10), 1300-1302.

Pender, F., & de Looy, A. (2004). Monitoring the development of clinical skills during training in a clinical placement. *Journal of Human Nutrition and Dietetics , 17*, 25-34.

Rouev, P., Memdzhiev, H., Spiridonova, J., & Dimov, P. (2004). Universal newborn hearing screening program in Bulgaria. *International Journal of Pediatric Otorhinolaryngology , 68*, 805-810.

Salina, H., Abdullah, A., Zamrato Mai-sarah Mukari, S., & Tamil Azmi, M. (2010). Effects of backgroudn noise on recording of portable transient evoked otoacoutsic emission in newborn hearing screening. *Eur Arch Otorhinolaryngol , 267*, 495-499.

Samii, R., Van Wassenhove, L., & Bhattacharya, S. (2002). An innovative Public-Private Partnership: New Approach to Development. *World Development , 30* (6), 991-1008.

Seligmann, T. J. (2001). An IDEA Schools Can Use: Lessons From Special Education Legislation. *Fordham Urban Law Journal , 29*, 759-790.

Shulman, A., Besculides, M., Saltzman, A., Ireys, H., White, K., & Forsmand, I. (2010). Evaluation of the Universal Newvorn Hearing Screening and Intervention Program. *Pediatrics , 126*, s19-s27.

Sininger, Y., Martinez, A., Eisenberg, L., Christensen, E., Grimes, A., & Hu, J. (2009). Newborn Hearing Screening Speeds Diagnosis and Access to Intervention by 20-25 Months. *Journal of the American Academy of Audiology , 20* (1), 49-57.

Snyderman, R., & Williams, R. S. (2003). Prospective Medicine: The Next Health Care Transformation. *Academic Medicine , 78* (11), 1079-1084.

Speros, C. (2005). Health Literacy: concept analysis. *Journal of Advanced Nursing , 50* (6), 663-640.

Spivak, L., Sokol, H., Auerback, C., & Gershkovich, S. (2009). Newborn Hearing Screening Follow-up: Factors Affecting Hearing Aid Fitting by 6 Months of Age. *American Journal of Audiology , 18*, 24-33.

Thompson, M., & Thompson, G. (February 1991). Early Identification of Hearing Loss: Listen to Parents. *Clinical Pediatrics , 30* (2), 77-80.

Tranebjaerg, L. (2008). Genetics of congenital hearing impairement: A clinical approach. *International Journal of Audiology , 47*, 535-545.

Uus, K., & Bamford, J. (2006). Effectiveness of Population-Based Newborn Hearing Screening in England: Ages of Interventions and Profile of Cases. *Pediatrics , 117* (5), e887-e893.

Yoshinagoa-Itano, C. (2003). Early Intervention After Universal Neonatoal Hearing Screening: Impact on Outcomes. *Mental Retardation and Developmental Disabilities Research Reviews , 9*, 252-266.

Yoshinago-Itano, C. (2003). From Screening to Early Identificationa dn Intervention: Discovering Predictors to Successful Outcomes for Children With Significant Hearing Loss. *Journal of Deaf Studies and Deaf Educations , 8* (1), 11-28.

Yoshinago-Itano, C., Coulter, D., & Thomson, V. (2001). Developmental outcomes of children with hearing loss born in Colorado hospitals with and without universal newborn hearing screening programs. *Seminars in Neonatology , 6*, 521-529.